Amputee identity disorder and related paraphilias

Robert C Smith

In 1933, a series of articles and letters in the journal *London Life* discussed the phenomenon of amputee attraction. Little then appeared until 1972, when the magazine *Penthouse* published an article on a definable group of people who were attracted to amputees. This was followed by a column on amputee attraction called 'Monopede Mania', which continued until 1978. The first academic article on the subject was published in 1977, when John Money described two cases of a condition for which he coined the term 'apotemnophilia' (Money *et al.*, 1977). Since then there has been a growing awareness of a group of people who have a sexual attraction to amputee partners or wish to be amputees themselves. This has been largely due to the effects of the anonymous communication provided by the internet. Most people with these conditions were secretive and many were unaware of any other sufferers. There are now probably several hundred internet sites devoted to the concept of amputee attraction (as well as attraction to other forms of disability such as brace wearers, the visually impaired and cast wearers). There are also a small number of sites devoted to the amputee identity disorder (AID) community, which is a much smaller group.

Terminology

Acrotomophilia – a paraphilia in which sexuoerotic arousal and facilitation or attainment of orgasm are responsive to and dependent upon a partner who is an amputee. Sufferers are known in lay terminology as 'devotees'.

Apotemnophilia – a paraphilia in which sexuoerotic arousal and facilitation or attainment of orgasm are responsive to and dependent upon being an amputee oneself. Sufferers are known in lay terminology as 'wannabes'.

Amputee identity disorder (AID) – a condition characterized by an intense desire to be an amputee and a feeling of incompleteness with a full complement of limbs. Sufferers are known in lay terminology as 'needtobes'.

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Pretender – this describes individuals who mimic the amputated state by the use of crutches, wheelchairs or adapted prostheses or by binding up their limbs. This behaviour is a feature of all of the above conditions but is commonest in the apotemnophile group. In the AID group it is called rehearsal activity.

This contribution focuses mainly on the non-paraphilic AID group.

Aetiology

There are no firm views on the aetiology of the condition and little research has been carried out. Most information is based on questionnaires from websites and individual case reports. Current views on aetiology include the following.

- The sight of an amputee in childhood imprints on the psyche as a desirable body image.
- The child feels unloved and by becoming disabled may attract the love and caring they feel is deficient. There are very strong positive thoughts about becoming an amputee.
- The desire is an external manifestation of an unresolved internal conflict.
- The condition is neuropsychological, in that there is an anomaly (anatomical or functional) of part of the brain representing the limb. Gender identity disorder (GID) has many similarities to AID and there is some evidence to suggest that male-to-female GID patients have a central nervous system anomaly (see also Green, 2004).

Epidemiology

The demographics of AID are very difficult to establish as few patients actually seek treatment specifically for the condition. Some patients seek treatment for associated psychiatric conditions but do not discuss the AID problem with their therapist, either because they are too ashamed of their feelings or because they feel the therapist will have no understanding of those feelings. The advent of the internet has led to more knowledge about the condition being available and has led to more cases being identified. However, attempting to identify the demographics through the internet is fraught with problems due to the anonymity of communication, which allows people to fantasize and misrepresent their true feelings for vicarious reasons. An internet survey carried out by an apotemnophile website produced over 200 responses, but many were frankly fantastical.

A carefully conducted telephone study (which has inherent problems of its own) from the Department of Psychiatry of Columbia University, New York, which identified over 50 patients, has suggested that sufferers tend to be well-educated, predominantly white, males and seem to include a higher than normal proportion of homosexuals, cross-dressers and transgendered individuals (>20%) (Michael First, personal communication, 2003). The most common desire was to be a unilateral above-knee amputee, but some desired to have more than one limb amputated (see Figure 1) and a few wished for an arm amputation.

The higher than normal proportion of homosexuals, transgendered and cross-dressers may simply be a sampling problem, as one of the key contacts was homosexual. It is likely that certain ethnic groups are less likely to present for cultural reasons and that men may be more likely to admit to their feelings than women. It

appears that a greater proportion of women wish to have more than one limb amputated but this too could be a sampling problem.

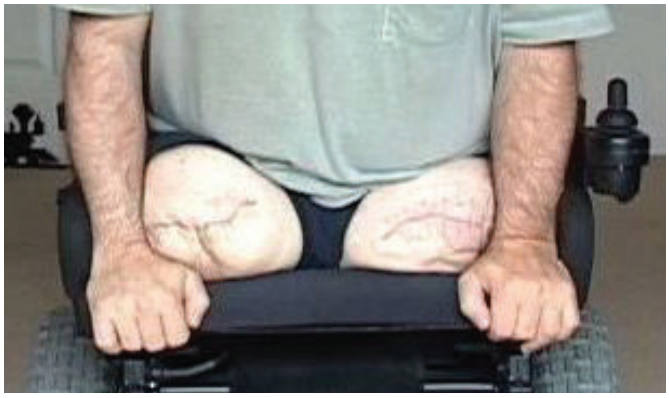
It is therefore very difficult to give a true impression of the worldwide demographics of this condition but it seems likely that there will be several hundred sufferers in the UK.

Clinical features

AID appears to develop in the early years, usually between the ages of 5 and 15. Most sufferers have a well-formed impression of their desired body image by the time they reach their teens. The trigger appears to be the sight of an amputee and many individuals can clearly recall the first amputee they saw resulting in a 'recognition' response of their hitherto vague feelings of discomfort. This may be as young as age 4 or 5. As mentioned above, there appears to be an increased incidence of homosexual, transvestite and gender dysphorics in this group.

The components of the condition vary in severity but the following symptoms are usually identified.

- A feeling of 'incompleteness and disability' as a four-limbed individual but a certainty of a feeling of 'completeness and enablement' after amputation.
- A fixed idea about the limb and the level of amputation required. This is most commonly a unilateral above-knee amputation, but sometimes manifests as a desire for an arm amputation, or even an amputation of more than one limb.
- A feeling of intense jealousy at the sight of an amputee.
- Feelings of shame and unworthiness about the feelings. These individuals feel completely alone and do not believe anyone else can suffer from such bizarre ideas. They may have been in psychiatric treatment without ever informing the therapist of their underlying desire.
- Repeated episodes of depression and occasional suicidal thoughts. Sometimes there have been plans of self-injury to achieve amputation such as by using shotguns, burning or deliberately infecting wounds.
- An apparent failure of the currently available psychiatric treatments to resolve their problem.
- Rehearsal activity (pretending) during which they imitate the amputated state in private and in public.



1 A successful 'wannabe'. Left above-knee amputation following self-injury; right above-knee amputation performed electively.

Differential diagnosis

In assessing AID patients it is important to eliminate other potential reasons to seek amputation. Stewart and Lowrie (1980) believe that self-mutilation, including amputation, chiefly occurs in five distinct groups of patients:

- transsexuals, who usually mutilate only the genitals in order to assume the physical appearance of the opposite sex
- schizophrenics who may self-mutilate in response to voices ordering them to do so or in response to a delusional belief that the body part is defective or 'bad'
- patients with a personality disorder, who appear to mutilate to relieve tension or gain secondary advancement
- confused patients, who may injure themselves due to disinhibition, poor judgement or perceptual difficulties
- depressed patients, who may mutilate themselves in a failed suicide attempt or as atonement for perceived sins.

Other groups of patients who may seek amputation include those with factitious disorder (Munchausen's syndrome) and body dysmorphic disorder (BDD). Those with BDD perceive the limb as being defective in some way, in contrast to patients with AID who see the limb as being normal but extra to their perceived body image. It seems that AID patients are similar to those transsexuals who amputate their genitalia in order to achieve their desired body image.

Treatment

Non-surgical treatment

Antidepressants (including selective serotonin reuptake inhibitors, SSRIs), psychotherapy, cognitive–behavioural therapy (CBT), hypnotherapy and electroconvulsive therapy (ECT) have all been tried with limited success. Anecdotally, the most useful pharmacological intervention is probably the use of high-dose SSRIs (personal communication).

Some patients notice a marked increase in the severity of their symptoms during times of stress, while others find that immersion in work helps to control the condition by distraction. Obviously when they retire or become unemployed the feelings become all-consuming. Some find that rehearsal activity (pretending) either at home or in public may relieve the tension temporarily. However, AID is a condition that appears never to be resolved by non-surgical therapy and the symptoms can only be suppressed.

Self-injury

Many sufferers have resorted to self-injury to achieve amputation: methods have included the use of chainsaws, shotguns, train wheels, a home-made guillotine and cold injury with dry ice (solid CO_2). Clearly these are dangerous activities and a number of patients have died as a result. Others have sought elective surgical amputation. One recent high-profile case in the USA involved an unlicensed surgeon who carried out a leg amputation which resulted in the death of the patient from gangrene. The surgeon was subsequently imprisoned for second-degree murder.

Elective amputation

A number of patients have successfully achieved elective amputation. There are anecdotal reports of amputees who have had amputations carried out by cooperative surgeons under subterfuge. The current author carried out two leg amputations in 1997

and 1999 and further amputations have since been carried out in a third-world clinic. The follow-up of these patients is clearly short, but all patients seem to be satisfied with the results. They feel 'enabled', their all-consuming desire is resolved, and they find they are leading more stable and more productive lives. An interesting additional point is that most are no longer interested in associating with or communicating with the 'wannabe' or 'needtobe' communities. This tends to make long-term follow-up difficult as individuals who have achieved amputation wish to put their previous unhappy, tormented life behind them and continue life in their idealized body form. They have often created a cover story as to how they achieved amputation and obviously fear their story will be shown to be false. The underlying shame and embarrassment about the condition persists, even after satisfactory resolution of the disorder.

Difficulties in treatment

Individuals with AID present major difficulties with management. Few therapists have knowledge of the condition and some have even treated patients without being aware of the underlying problem. Some therapists recognize the condition but others are unaware of it. Patients may present with self-injury or unusual medical symptoms and demand amputation. A case reported widely on the internet involved the use of dry ice to produce irreversible cold injury and there has been a similar case in the UK. Clearly, the risks of attempting amputation by self-injury are considerable and it is likely that some apparent suicides were in fact attempts to achieve amputation.

The current management of patients depends on accurate identification of the underlying problem and supportive psychiatric and psychological care. Patients may present with apparent accidental injury and demand amputation. Those who have achieved traumatic amputation may refuse reattachment surgery. Although it is contrary to the normal response of the medical carers it is probably wiser to accede to the patient's request provided a definitive diagnosis of AID has been made. Attempts at limb conservation or reattachment have a poor result as patients do not usually cooperate with rehabilitation measures. If the limb is preserved they are likely to re-present with a further attempt at injury.

Surgeons are unwilling to accede to AID patients' requests for amputation for a number of reasons.

- The deliberate mutilation by amputation appears to run contrary to the stricture that doctors should first do no harm. However, it may be more harmful to refuse operation in patients at risk of self-injury.
- The extensive and adverse publicity associated with the release of details about the patients on whom the current author operated has made surgeons and institutions wary of any involvement.
- There is a theoretical risk that surgeons may be prosecuted for assault even in the absence of a complaint by the injured party. For example, in the UK a recent prosecution of people involved in consensual sadomasochistic activity was successful.
- There is no long-term follow-up studies of patients who have succeeded in achieving amputation. The only long-term evidence is from self-injured amputees who certainly seem to have long-term successful outcomes.
- We do not know how the patient's quality of life with an amputation will be as they grow older and have increasing problems with mobility and cardiorespiratory reserve.

Relationship between amputee-related conditions and gender dysphorias

Amputee-related disorders	Gender-related disorders
Acrotomophilia ('devotee')	Gynandromorphophilia
Apotemnophilia ('wannabe')	Autogynophilia
Amputee identity disorder ('needtobe')	Gender identity disorder

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Suggested classification of amputee identity disorder

Body integrity identity disorder

- Gender identity disorder
- Amputee identity disorder
- Unspecified identity disorder (visual disability, paraplegia, brace wearers, cast wearers, crutch users, wheelchair users)

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The future for AID

At present there are no surgical units in the UK carrying out amputations on patients with a diagnosis of AID. There are some surgeons in third-world countries who are prepared to carry out these procedures but the standards of surgery and the quality of the facilities is unknown. In general, the patients are not fully assessed psychologically nor are they offered the chance of non-operative treatment.

An international group of professionals with an interest in the condition meet on an annual basis under the guidance of Professor Michael First of Columbia University to develop the criteria for diagnosis and hopefully to develop a research project to develop strategies for management. At present, it is unlikely that surgical treatment will be carried out until formal approval of a research project has been obtained. A prime role of the group is to explore the classification of the condition within the diagnostic criteria for psychiatric illnesses. The current view held by this group is that AID appears to be very similar in development, progress and response to treatment as GID and could possibly be included in the same diagnostic category. There are also similarities in the amputee-related paraphilias (and the other disability-related paraphilias) to the gender-related paraphilias (Figure 2). A possible classification of AID would place it in a classification with all the disorders of the integrity identity of the body (Figure 3). ◆

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INTERNET SITES

Amputee by Choice
http://groups.yahoo.com/groups/amputee-by-choice
(An internet group devoted to the apotemnophile and AID community.)
Body integrity identity disorder
http://www.biid.org
(An internet site run by the group looking into the development of a classification of AID and the prospect of trials of therapy.)
Need2be1
http://health.groups.yahoo.com/group/need2be1/
(An internet group for apotemnophiles and AID sufferers.)

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